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Clinicians' concerns about decision support interventions for patients facing breast cancer surgery options: understanding the challenge of implementing shared decision-making

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Abstract

Background There is interest in interventions that provide support for patients facing challenging decisions, such as the choice between mastectomy and breast conservation surgery for breast cancer. However, it is difficult to implement these interventions. One potential source of resistance is the attitudes of clinicians.

Objective To examine specialist breast clinicians' opinions about the provision of decision support interventions (DesIs) for patients.

Methods As part of the development of a web-based DesI (BresDex), semi-structured interviews were conducted with specialist clinicians [breast surgeons, breast care nurses (BCNs) and oncologists] from four breast units in a UK region, and speciality national opinion leaders. Interviews were recorded, transcribed and analysed using the Framework approach.

Results A majority of the 24 clinicians interviewed did not have a working knowledge of DesIs and were ambivalent or sceptical. Many expressed conflicting opinions: they noted the potential benefits, but at the same time expressed reservations about information overlap, overload and about content that they considered inappropriate. Many wanted access to DesIs to be always under clinical supervision. In particular, they were uncertain as regards how DesIs could be tailored to individual patients' needs and also accommodate clinical practice variation. BCNs were particularly concerned that DesIs might induce patient anxiety and replace their role.

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Conclusions The concept of providing interventions to support patients in decision-making tasks generated concern, defensiveness and scepticism. These attitudes will be a significant barrier. Implementation efforts will need to recognize and address these issues if these interventions are to become embedded in clinical practice.

Background

Providing choices to patients has become an increasing priority of health service providers in the last decade, with the hope it will improve equity in healthcare service and delivery,^{1,2} enhance the process of care,^{3,4} and optimize both patients' psychological recovery⁴⁻⁹ and treatment satisfaction.^{3,4,10} The successful involvement of patients in decision-making requires the provision of choices along with an explanation as to why they are being offered a role in decision-making,¹¹ together with the provision of high quality information^{11,12} and sufficient time to deliberate the options.

Patient Decision Support Interventions (DesIs),¹³ also known as decision aids or decision support technologies, are designed to 'help people make specific and deliberative choices among options by providing (at the minimum) information about the options and outcomes that are relevant to a person's health status'.¹⁴ The addition of DesIs to routine clinical practice has been associated with enhanced patient involvement in healthcare decision-making,^{15,16} with improved knowledge and risk perceptions, decisions which were more consistent with patients' personal values, improved patient satisfaction with decision-making^{15,16} and enhanced quality of life.¹⁶ DesIs could facilitate optimisation of patients' healthcare decision-making experiences by extending information provision and decision support currently available from clinical teams;¹⁵ supporting, but not replacing the central relationship between the patient and their treating clinicians.

The surgical treatment of breast cancer is a classic example of a preference-sensitive decision in healthcare; patients' preferences can often direct treatment due to clinical equipoise,

as neither treatment option [Breast Conservation Therapy (BCT) or mastectomy] is superior in terms of survival (in cancers up to 5 cm diameter),¹⁷⁻¹⁹ physical or psychological morbidity (except body image).^{8,20,21} Patients are known to possess different treatment preferences based on individual concerns and values,²²⁻²⁶ creating a clinical context where DesIs are of potential value. They have been developed elsewhere for breast cancer patients facing treatment decisions,¹⁶ but at present, one does not exist for this UK patient group. The development of a web-based DesI has been proposed to improve the flexibility and accessibility of such interventions, and provide relevance within the UK.²⁷

Although research demonstrates potential benefits to patients of employing DesIs as adjuncts to support patient healthcare decision-making,^{15,16} little is known about clinicians' attitudes towards such technologies except that they tend to lack awareness of DesIs.²⁸ As gatekeepers of patient information, awareness of clinicians' views regarding DesIs is crucial to their successful widespread implementation into clinical practice. Information currently available on clinicians' perceptions of the barriers and facilitators to DesIs are mainly found within publications about implementing shared decision-making in clinical practice, which include some examples where DesIs were employed.²⁹ The most frequently reported barriers included time constraints²⁹⁻³¹ and perceived lack of applicability due to patient characteristics.²⁹ The most commonly reported facilitators included provider motivation, and a positive impact on both the clinical process and patient outcomes.²⁹

The extent to which developers consult with both patients and clinicians during the development of DesIs varies. A systematic review of

information in DesIs identified a total of 98 DesIs (68 treatment focused and 30 screening focused) which specifically described the development or implementation process.³² Approximately 80% employed external consultation within the process, with a trend to primarily seek expert guidance; mainly comprising small group or panel discussions with experts or clinicians, rather than the obtainment of more detailed information through individual discussions.

The successful implementation of DesIs into routine practice is likely to require not only adherence to quality criteria, as established by the International Patient Decision Aid Standards (IPDAS),³³ but for clinicians to accept and embrace such technologies.^{28,34} The aim of this study was to explore individual specialist clinicians' views of the design, acceptability and implementation of a DesI for UK women with breast cancer eligible for a choice of therapeutic surgery; seeking specialists' perceptions of DesIs in general, their impression of web-based versions and the employment of DesIs within therapeutic breast cancer surgery. We conducted this study as part of the BresDex project: developing a web-based decision support for women offered surgical options for breast cancer.

Methods

Study design

Qualitative methods were employed to explore the views of specialist breast clinicians regarding the design and acceptability of a DesI for women with breast cancer, in whom BCT is not contraindicated. Semi-structured interviews were chosen for their capacity to capture rich data on topics of pre-determined interest, while providing sufficient flexibility to identify emergent themes in allied areas of interest.

Sample and setting

Approval to conduct the study was obtained from the Multicentre Research Ethics Committee of Wales, local research ethics and NHS Trust research governance committees. Thirty

seven eligible specialist breast clinicians were invited to participate in the study; including thirty-three clinicians from four breast units within a UK region and four national opinion leaders with expertise in the surgical, oncological and psycho-oncological management of breast cancer. Eligibility was based on the inclusion and exclusion criteria outlined below.

Inclusion criteria

- Willingness to be interviewed about this area of clinical practice.
- Experience of consultation with women facing breast cancer treatment decisions or expertise in the management and decision-making experiences of women with breast cancer.

Exclusion criteria

- Clinicians who were not permanent specialist members of a multi-disciplinary breast team.
- Clinicians not routinely involved in discussing breast cancer treatment decisions with patients or those lacking expertise in the field.

The semi-structured interview topic guide was developed collaboratively by the multidisciplinary research team, including three specialist breast team clinicians [two surgeons and one breast care nurse (BCN)], two academic general practitioners, four non-clinical researchers, two National Breast Screening Programme representatives and a consumer representative who had previously been treated for breast cancer. The topic guide explored clinicians' opinions and experiences of decision-making among UK women with breast cancer given a choice of surgery, and their opinions regarding the design, acceptability and implementation of a DesI, including the scope, content and administration of such an intervention. As part of the interview, clinicians were given a synopsis of what DesIs are, and were shown a paper copy of an early prototype of BresDex to stimulate discussion. Interviews were digitally recorded and transcribed verbatim. All data were anonymised and stored securely.

Data analysis

Qualitative data analysis followed the National Centre for Social Research's 'Framework' Analysis.³⁵ This rigorous, comprehensive, systematic approach is particularly suited to the analysis of qualitative health services data, where the research questions are more directed and goal oriented than with other forms of qualitative research. Analysis proceeded through the stages of familiarization, identification of a thematic framework, charting, mapping and data interpretation.³⁵

Results

Of the thirty-seven specialist clinicians approached, twenty-five agreed to participate in the study. The non-participants comprised eight BCNs, three surgeons and one surgeon opinion leader. In addition, one surgeon agreed to participate, but later withdrew due to interview scheduling difficulty. Interviews were undertaken over a seven-month period from May to November 2008 with 24 specialist breast clinicians, 21 NHS breast team clinicians (seven consultant surgeons, nine BCNs, four oncologists and one radiotherapy technician), and three national opinion leaders (a consultant surgeon, oncologist and nurse consultant). The interviews were conducted in the clinicians' work environment by two non-clinical researchers (KC and KW) and varied in length between 25 and 60 min.

The clinicians interviewed had very limited pre-existing knowledge or experience of patient DesIs. Despite this, most were generally positive about such interventions and regarded them as potentially useful in enhancing both the information provided and the decision-making support offered by clinicians.

Many felt, however, that this type of decision support was only likely to benefit specific patient groups, particularly those finding decision-making challenging and who also had sufficient technological skills to use a computer or access a web-based system. Clinicians also expressed the view that to be of use, the DesI would need to be designed and developed sensitively and always in

conjunction with clinicians and patients, and evaluated among the intended patient group prior to dissemination.

The interviews generated five main themes; views about the nature and quantity of content information in a DesI for breast cancer surgical options, views about which information should be omitted from the decision support, views about the presentation style, the introduction and exact mode in which patients used DesIs, and the perceived challenges to the implementation of a DesI into clinical settings. In addition to perceived implementation challenges, clinicians conceptualized a number of challenges related to content and accessibility, which are detailed within the other themes and summarized in Table 1.

Clinicians' views about the nature and quantity of content information in a DesI for breast cancer surgical options.

The clinicians felt it important that the information to be included should be organized around four main headings; treatment options, factual content, patient experience video clips and photographic images.

Treatment options

All clinicians expressed the view that a breast cancer surgery DesI should primarily focus on the most relevant treatment options that patients need to consider: BCT or mastectomy. Many also felt that immediate and delayed breast reconstruction should probably be included, along with basic information on neo-adjuvant chemotherapy to increase the potential scope of BCT.

Clinicians, however, expressed the view that the range of possible techniques involved in both BCT and breast reconstruction could pose a potential problem in terms of the locally available options, treatment descriptions and potential outcomes.

...[the DesI] is potentially going to a bit provocative...because...We have all got our own ways of doing it [BCT]. Some...do a wide local excision leave a big dent, some...think much more carefully

Table 1 Clinicians' perceived challenges to DesIs

Content
Which treatment options to include
Level of information detail
The inclusion/type of survival and prognosis data
The inclusion of photographic images
How to accommodate heterogeneity of clinical practice
How to tailor to patient and information need heterogeneity
Accessibility
Potentially constrained by clinicians' willingness to inform patients about the DesI
Potentially constrained by patients' technological skills, and computer or internet access
Implementation
Clinician reservations and uncertainty of how DesIs can assist patient decision-making in the context of pre-existing information resources and sources of decision support
Clinician concern that a DesI might cause information overload
Clinician concern that a DesI could cause patient distress (especially photographic images and prognostic data)
The correct identification of patients to receive a DesI to (all patients given a choice or only those actively seeking a role in choosing their treatment)
Timing of the DesI presentation to patients and potential workload implications [especially breast care nurses (BCNs)]
Clinician concern that DesIs could be perceived as a potential replacement for the highly specialized BCN role
Clinician concern regarding a DesI retaining its relevance within an area of rapidly changing clinical practice (options and techniques)

[about] placement of scars,...breast reshaping...using advanced onco-plastic techniques. So how are you going to cover all that? And if you do, are you going to have patients coming along saying...I want it done like that, to a surgeon who is not able to offer them that. (HCP014, Consultant Breast Surgeon, Opinion Leader)

Factual content

Most clinicians felt the DesI should provide core information about BCT and mastectomy, with or without immediate reconstruction, including their possible advantages and disadvantages.

I think you have got to say the advantages and disadvantages of breast conservation, advantages...overall survival is the same...you can get a very good cosmetic result...Disadvantages...a higher local recurrence rate, which may require further treatment... (HCP012, Consultant Breast Surgeon)

Almost all vocalized the opinion that the DesI should include clear, concise unambiguous information on recurrence rates.

...if you [are]...going [put] something in there about the risk of a recurrence. That has to be put in a very unambiguous terminology...very easy to under-

stand so you can't switch the figures round and make a risk sound worse than it is, or leave anything open to misinterpretation... (HCP002, BCN)

Some, however, felt that the presentation of recurrence data was not particularly straightforward due to the complexity and variability of the data and that this lack of clarity might influence patients' decisions.

I think the single biggest challenge for a DesI that I don't think people get told about at the moment is that the rate of local recurrence is double if you have lumpectomy and radiotherapy than it is if you have mastectomy...[but] overall, the survival rate is the same or there is some survival benefit from radiotherapy at fifteen years, but that tends to be...where the recurrence rates are high...but...one in four recurrences results eventually in a metastasis and death, and so if you have a higher local recurrence...which you do in breast conservation, there may be a small excess mortality from that. I don't think many people are talking about that because if you do you push everyone towards mastectomy. (HCP012, Consultant Breast Surgeon)

Several clinicians felt that the intervention should include an outline of the different breast reconstruction options available. They also expressed the view that patients needed to understand that reconstructive procedures are

specifically tailored to individual patient requirements.

...I think the things to get over are that there is more than one way of doing it, not everybody will be suitable for every type. (HCP011, Consultant Breast Surgeon)

There was a general view that it would be beneficial for the DesI to include basic information on neoadjuvant chemotherapy and radiotherapy, including their common side effects: hair loss, nausea and vomiting, infertility and infection risks for chemotherapy; tiredness, skin soreness and breakdown, potential breast and lung fibrosis, cardiac injury and a small risk of secondary cancers for radiotherapy.

Clinicians suggested that the DesI might also include information on usual treatment timelines, sexual function, psychological outcomes, anaesthetic risks, diet, male breast cancer, clinical trials and specific information for partners. Some also wondered whether the intervention should include information specifically designed for ethnic minority groups and those with learning disabilities.

Patient experience video clips

Most clinicians felt that video clips of patients' experiences would be useful inclusions within the DesI. One felt video clips could prove particularly useful for patients with poor literacy.

Photographic patient images

Photographic images showing post operative results were felt to be of great potential value within the DesI for their ability to demonstrate the range of potential aesthetic outcomes (good to poor) for the various treatment options.

Photographs of women who have had mastectomies,...wide local excision surgery [BCS]...radiotherapy reactions...breast reconstructions, showing good and bad results. (HCP007, Consultant Breast Surgeon)

There was, however, concern expressed by BCNs in particular that some patients accessing such images in an unprepared state might

become distressed. These clinicians felt that patients might benefit from being warned about the nature of such images, so that they could decide whether to proceed, and if so, were prepared. Alternatively, some suggested that access to the DesI should be limited to being under the supervision of BCNs.

Views about which information should be omitted from the decision support

The main topic of contention was whether survival and prognosis data should be included in the DesI. Many felt that if survival and prognosis data were incorporated, it was essential that the content was very sensitively portrayed and should comprise only a very basic level of information.

Clinicians generally felt that at diagnosis, most patients simply wanted to be reassured that they were going to survive. While clinicians were happy reassuring women presenting with early breast cancer about good survival data, their concern was that the prognostic data for those presenting with more advanced breast cancer were a lot worse and that the provision of this information could prove unhelpful and upsetting at this stage of treatment decision-making. Most clinicians expressed the view that prognostic information was difficult to communicate sensitively and ideally should only be provided 'face to face' by clinicians.

...patients trying to work out their prognosis without input from the clinician is quite dangerous. There are web sites...but...you need a certain amount of medical knowledge to interpret them. They are meant to be physician tools... Patients find them and... sometimes can be quite shocked by the [prognostic] information they get back....I think that's something that should be discussed patient to doctor... (HCP006, Clinical Oncologist)

They also expressed reservations about providing prognostic information at the time of diagnosis and surgical decision-making; believing it better deferred until patients' post operative pathology results were available, therefore permitting a more accurate individualized assessment of prognosis.

...obviously we can't withhold information from people and they do have to have a very frank discussion about things like long term prognosis and survival rates, but I would suggest the best time to do that is when you see them with their final pathology results after the their surgery... (HCP014, Consultant Breast Surgeon)

Views about the presentation style of a DesI

Clinicians' views about the presentation style of the DesI centred on the medium used, language style and terminology. There was general consensus that the medium should be user-friendly, and that it should be written in language which is clear, concise and free from medical jargon.

...I do think we need to avoid...medical jargon and...abbreviations. (HPCD005, BCN)

Clinicians were unsure, however, as regards at what point on the spectrum of simplicity to complexity, the DesI should be pitched. They also questioned how DesIs could tailor to individual patients' intelligence and pre-existing knowledge, and their information needs.

This [DesI] has [to be]...written for a general...one size fits all, you can't tailor it that much can you...[and] some people do want to know absolutely every minute possibility and every statistic... (HCP002, BCN)

...I think you have [to have] a core level of information and if people want to know more they can access additional levels. (HCP006, Clinical Oncologist)

The introduction and exact mode in which patients used DesIs

Clinicians felt that DesIs should be introduced to patients by their BCNs, and that they were likely to provide the greatest potential benefit when made available at an early stage in the process of consolidation and exploration of information, when patients received other supporting information and were starting to consider their options and preferences in the light of factual treatment information.

There was a general perception amongst clinicians that patients tend to identify many issues they want to explore regarding their cancer and its treatment between the period of initial information provision at diagnosis, and the subsequent consultation with their BCN several days later. It was therefore felt that this period between consultations was the ideal time for patients to utilize the DesI to reinforce the information provided by the breast team, expand their knowledge further and start to explore their preferences in the context of this knowledge. It was thought patients would then have a more informed basis on which to have further one-to-one treatment discussions with their breast clinicians.

Clinicians held mixed opinions on whether patients should be guided or supervised by a BCN while using the DesI, or whether patients should use it independently. Some felt that their use should be supervised to avoid misinterpretation of information, and provide support to patients who might become distressed or require technical assistance during its use.

I think it should be used with somebody in the room with them, I don't think it should be used unsupervised...[or] accessed in an unsupervised way just off the internet, because I think they would need to have somebody sitting with them who could talk to them about all the queries that they are going to have. (HCP007, Consultant Breast Surgeon)

Others acknowledged that patients might wish to explore such decision support independently, outside the clinical environment.

Perceived challenges to the implementation of a DesI into clinical settings

Despite many generally positive comments about the potentially beneficial role of DesIs in supporting patient decision-making, clinicians also perceived challenges and expressed reservations about their use. Nine main challenges to the implementation of DesIs into practice were identified. These are described below.

Unnecessary addition to current information provision and decision-making support

One of the key issues for some clinicians (predominantly BCNs) was the feeling that DesIs would not add anything to the wealth of pre-existing information available to this group of patients in verbal, written and web-based forms, and the decision support currently offered by specialist breast clinicians.

...it just doesn't seem to be adding anything to what patients should be getting told in the clinic. (HPCPD014, BCN)

In particular, clinicians questioned how the DesI would differ from these pre-existing resources.

Information overload

Clinicians raised the concern that a DesI might overwhelm patients with information. They felt that patients were already exposed to large volumes of information and had a relatively short time to assimilate and use this for decision-making. They were concerned that an additional resource might detract from rather than enhance the process.

The thing that really bothers me is they are saturated with information from the surgeon, from us; our waiting times are very short at the moment, so the turnaround sometimes can be...diagnosis Friday...in the theatre the following Tuesday. They are saturated on that Friday the whole weekend is a blur, and they have got this [DesI] to look at as well... (HPCPD009, BCN)

Uncertainty regarding the ability of a DesI to tailor to individual patient needs

A number of BCNs in particular expressed that it was 'patronizing' to think that a computer- or web-based intervention could enhance or replace the individually tailored, two-way, face to face discussions between clinicians and patients which informed and supported patient decision-making. They felt that the key to the success of the BCN role was the ability to tailor information, communication and decision-making support to individual patients' highly specific needs.

There is a lot of skill in tailoring information to the patient that a computer tool can't replace. I think there is a little bit of scepticism about the usefulness of it...I don't think that a computerized programme or DVD can replace a face to face consultation... (HCP002, BCN)

...if you have got the person in front of you and they are...becoming more visibly distressed, you would back off, or...offer emotional support...I think there might be concern that a decision-making tool is by its nature more...cold and clinical... (HCP019, BCN opinion leader)

Uncertainty regarding the interactive decision-making aspect of the DesI

There was also some scepticism articulated about how the proposed interactive decision-making component of the DesI could assist patients' decision-making process. One of the potential interactive tools discussed was a self ranking exercise to help patients prioritize the most important factors driving their choice.

If I was a patient and I was asked to list these [factors] in order of importance [to making my decision] my number one thing of importance would be chances of living or dying, does that help me make a decision whether I want to keep my breast or not? No. Because it's completely irrelevant to the surgical choices that you are being offered. Chances of cancer coming back does that help me make a choice, well no... (HPCPD014, BCN)

How to account for variation in practice

A recurring theme was how a DesI could accommodate for the existence of variation in clinical practice in both the options available to patients and the surgical techniques used. Variation in the availability and rationing of reconstructive techniques were also viewed as particularly problematic. Clinicians were specifically concerned about how a DesI might influence patients' treatment expectations.

...this other issue is particularly [important] in the smaller [breast] units...not doing reconstruction...if you are going to be...putting reconstruction much more on the agenda...how are [these] units going to cope with the demand... (HPCPD014, Consultant Breast Surgeon, Opinion Leader)

They also articulated that treatment practices change rapidly over time and therefore this resource would need to be regularly updated to retain its relevance to clinical practice.

...these things go out of date very quickly so it's how you fund an updating programme for them... (HCP012, Consultant Breast Surgeon)

Concern that patients may access information they are unprepared for

Although clinicians agreed that patients should not be denied information, some voiced concerns that in using the DesI, patients might encounter information that they were unprepared for, which might cause distress or anxiety. They particularly questioned whether entrance to the more 'sensitive' components (photographic images and prognostic data) should be via gateways advising patients about what they were about to access. Clinicians felt that this would enable patients to choose actively whether or not to view certain aspects of the DesI. Clinicians, however, acknowledged that encountering material which may cause distress is an existing possibility among patients utilizing web-based resources.

Concern that a DesI could devalue or replace the role of the clinician

One of the main reservations of clinicians was that DesIs might be perceived as a standalone intervention and thus a potential replacement for the individualized face-to-face consultations between clinicians and their patients. They felt strongly that DesIs should be viewed as an adjunct to the information and decision support provided by clinicians in verbal and other forms.

I think some are a little worried that you are trying to do us out of a job. But I don't think that a computerized programme or DVD can replace a face to face consultation... (HCP002, BCN)

BCNs were specifically concerned that the introduction of a DesI into routine practice might lead to a poorer quality service and support for patients. In particular, they feared that one result might be the replacement of the

specialist and therefore more expensive BCN, with a less highly qualified, less expensive nurse who would merely go through the DesI with patients.

Time and resource implications

Clinicians expressed concern regarding the potential time and resource implications of implementing a DesI into routine clinical practice. Some felt that it might increase the workload of BCNs in particular, through the need to introduce and explain what they were, provide support for their use and answer additional queries they might generate. BCNs were principally concerned that their limited resources and time with patients might be diverted from their established roles in the provision of information, and both decision-making and emotional support.

It's probably going to make us more work rather than less work...Because the vast majority of people don't want to see you three and four times before surgery, and I am just wondering if they have got questions that arise from what they see on there [the DesI], whether they will want to come back and discuss it again... (HCPCD006, BCN)

Accessibility issues

Clinicians acknowledged that patients' access to such a DesI was unlikely to be universal. They felt that accessibility might be constrained by a number of factors, including clinicians' definitions of which patients are eligible for a choice of surgical treatment.

I know of at least one colleague nationally who will not do mastectomy for someone who wants it if they are eligible for lumpectomy. He will say you have to find another surgeon...there will always be places,...[and] people around the country who will not support a patient who wants a mastectomy who is eligible for lumpectomy. So they will not use [such] a tool [DesI]...because patients aren't being given a choice... (HCP012, Consultant Breast Surgeon)

They also felt that patients' technological skills and access to equipment or the web would limit the potential value of DesIs to a wider group of patients. In particular, clinicians felt

that older patients (especially those over 65) were less likely to utilize such an intervention. Several suggested that this type of accessibility barrier could be overcome by making them available within breast clinics, with or without BCN support.

Discussion

Principal findings

A majority of clinicians were not aware of developments in the field of shared decision-making and the increasing interest in DesIs for patients. After being informed, most were generally ambivalent and many were either sceptical or held negative opinions. They articulated that such interventions might benefit patients as supplementary resources for those making treatment decisions, but at the same time expressed marked reservations regarding their content and potential usefulness. Clinicians' reservations were mainly based on concerns about how such an intervention differed from pre-existing information resources, how they could tailor to highly specific patient needs, and concerns that they could cause information overload and distress. They felt that it was too difficult to develop a useful decision support for patients due to the heterogeneity of patient information needs and information-handling, diverse patient web-access, and the heterogeneity and fast-changing nature of clinical practice. They were also unsure of the extent and nature of information to be included: which treatment options, at what level of detail, whether survival and prognosis data should be provided, and whether photographic images of women after surgery should be available. They did not raise the counter-argument that some patients might want such data and there was a general view that access to the instrument would be governed by clinicians' willingness to inform patients about the intervention, seemingly unaware that patients may search for such information and wish to know which sources they should trust. Many expressed the view that the DesI should not be freely available and that clinicians would

select which patients were given access. There were also concerns about practical issues – where and when the tool should be used – and a possible negative impact on professional roles, where clinicians may feel threatened by the arrival of a web-based interactive decision support resource.

Strengths and weakness of the study

The strength of this study and method is that it reports one of the first studies to explore in depth the views of clinicians who are already actively supporting women facing the difficult choice between mastectomy and BCT. Their critical responses are proof of how seriously they considered the topic, and the qualitative interviews provided the opportunity to explore their concerns in detail. Our study could potentially have been improved if we had been able to interview clinicians at many other breast units as we know that diverse views exist on this subject. Nevertheless, we are reassured by our analytical methods that data saturation was achieved and that this article represents a valid appraisal of professionals' views towards DesIs.

Results in the context of other studies

Clinicians are one of the most powerful gatekeepers to patient information. Their views and willingness to implement new technologies,^{28,32,34} together with the capacity for DesIs to operate within the existing healthcare process are likely to prove the critical factors in the successful and widespread implementation of DesIs into clinical practice. These results add new insights to the existing literature and indicate the deep professional reservations about supporting patients to become empowered, to become informed and to gain the ability to participate in decision-making activities.

Implications

These results provide sobering data for those who advocate the use of patient decision support. Many of the clinicians articulated a desire

to control or restrict the topics of information available to patients – specifically survival and prognostic data, and photographic images, and to supervise patients' access to the DesI to minimize 'distress and anxiety'. Few clinicians seemed to accept that their patients are likely to increasingly search for and access information resources outside the clinician's control.^{32,36} Many BCNs were also opposed to patients utilizing an independent intervention to increase knowledge or stimulate engagement in decision-making, in the belief that the intention was to replace their skills as patient advocates. Previous work has emphasized many practical issues, such as time constraints and the applicability and specificity of DesIs.^{29,32,33,37–39} This study confirms that these are factors, but also highlights a much more important issue which probably lies at the heart of the implementation challenge: many clinicians do not yet fully accept that patients are capable of becoming informed to the level where they are able to formulate ideas about their preferences and therefore take part in key decisions. Understandably, many patients actively seek additional information, and the internet has become a popular source.⁴⁰ Clinicians are rightly concerned about the quality of such information resources and can express a desire to protect patients from inaccurate or misleading information. However, in so doing they run the risk of appearing controlling or defensive about their role in advising patients about their disease and its treatment. BresDex was designed to address these concerns by ensuring adherence to evidence, involving all stakeholders, undergoing a 3-year development phase, a detailed evaluation and complying with quality standards.

It is recognized that it is very difficult to implement DesIs into clinical practice settings.³⁷ This study reveals the extent and depth of professional concerns about patient DesIs. Unless developers and those wishing to implement these interventions fully understand and work with clinicians to address and manage these concerns, there is very little chance that these methods will gain ground in clinical settings.

Conflict of interest statement

No competing interests have been declared.

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Role of the funding source

Cancer Research UK played no role in study design, collection, analysis or interpretation of the data, or in the preparation of the manuscript. The views expressed are those of the authors and not necessarily those of Cancer Research UK.

Authors' contributions

LC was involved in the conception and design of the study, the acquisition of funding, made substantial contributions to the acquisition of the data and analysis, and was involved in the drafting and substantially revising the manuscript, and gave final approval of the version to be published.

KC made substantial contributions to the acquisition of the data and analysis, and was involved in the drafting and substantially revising the manuscript, and gave final approval of the version to be published.

MWR was involved in the conception and design of the study, the acquisition of funding, substantially revising the manuscript for critically important intellectual content, and gave final approval of the version to be published.

SS was involved in the conception and design of the study, the acquisition of research ethics approval, revising the manuscript for critically important intellectual content, and gave final approval of the version to be published.

AC was involved in the design of the study, provided substantial comments for the revision of the manuscript, and gave final approval of the version to be published.

JA was involved in the conception and design of the study, the acquisition of funding,

provided substantial comments for the revision of the manuscript, and gave approval for publication.

JP was involved in the conception and design of the study, and bringing together the BresDex research group, she also provided comments for the revision of the manuscript, and gave final approval of the version to be published.

GE was involved in the conception and design of the study, the acquisition of funding, revising the manuscript for critically important intellectual content, and gave final approval of the version to be published.

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Appendix 1

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